

Using Valuable North Carolina Resources to Save Babies!

WE'VE COME A LONG WAY TEAM!

Late in 2000, advocacy efforts and legislative support provided funding to move toward statewide expansion of the North Carolina Folic Acid Campaign, as designated by the NC Folic Acid Council. The activities undertaken by collaborating organizations truly propelled the North Carolina Folic Acid Campaign forward quickly and strongly. These organizations included the Fullerton Genetics Center in Ashville, the March of Dimes, the NC DHHS Division of Public Health and the NC Folic Acid Council. Working within a short time frame, they moved the life-saving folic acid message to the forefront of public health programs in North Carolina. **The past six months have produced enormous awareness about folic acid among health department staff, volunteers, health care providers and women.**

Thanks to the funding from the State Legislature, the NC Partnership for Children, the March of Dimes, AND the hard work of over 44 mini-grant recipients, activities in 73 counties between January and June 2000 produced the following results:

- **Over 120,000 women heard about folic acid** from their health care provider or through a community agency or business!
- **Over 3,000 health care providers** received comprehensive information about folic acid as well as resources and ideas for integrating this message into their daily practice.
- **About 207,000 "reminder" items** and hundreds of thousands of flyers were put into the hands of women of childbearing age to help them remember to take their vitamin every day.
- **35,000 reminder stickers** were distributed along with **500 folic acid videos** and **over 9,000 posters.**

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HOLD THAT DATE

Folic Acid Council Videoconference Schedule:

Dec. 13, 2001	9:30 am–11:30 am
Mar. 5, 2002	9:30 am–11:30 am
Jun. 4, 2002	9:30 am–11:30 am
Sep. 5, 2002	9:30 am–11:30 am
Dec. 5, 2002	9:30 am–11:30 am

Held in 10 sites statewide—call Cindy Chambers at 1-866-GET FOLIC for the location nearest you. ♦

www.GetFolic.com



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ADVOCACY Corner

This year State Senator Purcell and State Representative Mia Morris, long standing heroes, were joined by Senator Eleanor Kinnaird, Representative Verla Insko and the Women's Caucus at the NC General Assembly to support the NC Birth Defect Monitoring Program and Folic Acid Campaign. Their efforts, along with the unwavering diligence of Jack McGee (Public Affairs consultant for the March of Dimes), March of Dimes staff, volunteers and Council members have kept small but significant folic acid legislation alive. When the final budget was passed, it included \$400,000 in one-time funding for the Folic Acid Campaign and \$125,000 in recurring funds for the NC Birth Defect Monitoring Program. While these amounts are less than originally requested, the Council still considers them a success in light of the severe budget deficiency in 2001. It is important to educate legislators about the need for folic acid education, the high rates of infant morbidity and the unacceptable rates of infant death in North Carolina year round. Please make it a point to

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A DAY IN THE LIFE of A CHILD with SPINA BIFIDA

Each day with my four year old daughter is one day more than I ever thought possible. Delia amazes me with her resilience, and love for life and the people around her. The reason David and I are so passionate is because she is. Already, at age four, Delia has a desire to educate people about spina bifida and prevention through taking a multi-vitamin everyday. It is our goal to educate every person humanly possible in order to lower the numbers of children born with spina bifida and neural tube defects. Hopefully, by giving you a peek into her life, you will find a reason to tell one person about taking 400mcg of folic acid a day to help prevent spina bifida and neural tube defects.



Delia

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GREATER PIEDMONT REGION

This spring March of Dimes staff, volunteers and Folic Acid Council members representing Anson, Cabarrus, Cleveland, Gaston, Lincoln, Mecklenburg, Richmond, Stanley and Union counties came together to design and implement a dynamic folic acid campaign. Three in-service educational sessions were conducted for 80 different health care providers, including university health center physicians, nurses, health educators, pediatricians, pediatric nurses, office managers and school health nurses. The project reached a total of 94 health care sites where about 6,500 women received direct education about folic acid—where most received either a bottle of multivitamins or a coupon for a bottle of multivitamins. Folic acid information was also given to health care providers at physicians' offices, rural health centers, a dental office, pharmacies, student health centers, a parish nurse and local health departments to assist them in passing this vital message along to their patients.

The project also reached women through **Winn-Dixie grocery stores, beauty salons, bridal registries, YMCA and Gold's Gym sites, worksites** (such as **US Airways Flight Attendants**), numerous **places of worship, marriage license bureaus, schools, child care providers and college campuses**. The media played a significant role in this campaign through radio and newspaper ads encouraging women to visit a local Winn-Dixie store to pick up a free bottle of multivitamins with folic acid. Data from a questionnaire on the redeemed vitamin coupons indicated that 62% of women aged 15–44 did *not* currently take a multivitamin everyday. By redeeming the coupons, women who previously did not take multivitamins on a daily basis now have an opportunity to begin!

The target audience was reached through creative means such as advertising for the free vitamins on radio programs that had large female audiences and sending out free vitamin coupons along with Medicaid cards to pregnant women and Medicaid recipients with children. A collaborative effort between many partner agencies, with the common goal of promoting the folic acid message, was essential to the success of the project. ♦



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psst...here's a TIP!

A surprisingly high number of health care providers *do not take a daily multivitamin with folic acid*—about 65%! Experience gained this spring suggests that if a presenter can convince providers to begin to take a multivitamin, then those providers are more likely to tell their patients! ♦

The Folic Acid Council now has a series of new ways for members to be involved! There are a number of committees that need YOUR help to be successful. Please contact either Lisa Richardson or Cindy Chambers at 1-866-GET FOLIC if you are interested in any of the following committees: Membership and Bylaws, Resource Development, Advocacy, Evaluation, Recurrence Prevention, Health Care Provider Education and Public Education (includes media). Regional Councils can use your help too! ♦



The Fullerton Genetics Center of Mission St. Joseph's Health System received \$95,000 in legislative allocations in the fall of 2000 to develop and implement an intensive folic acid education campaign in 17 counties of western North Carolina. The Center began by strengthening the regional Folic Acid Council to include 65 representatives from all over western North Carolina. These partnerships were key to the campaign's ability to reach into a variety of communities and agencies.

Spotlight on the Fullerton Genetics Center

The first component of the campaign was done in collaboration with the NC American College of Nurse Midwives and focused on presentations to 83 public and private healthcare provider settings. Providers at each site received a box of supplies and campaign items. This proved very popular. They also received *Ask Me About Folic Acid* buttons and were rewarded when "caught" wearing them. Because approximately 80% of the practice sites had limited time and space, many of the presentations were only about 20 minutes long. The Center developed a six minute folic acid video targeting health care providers for use with these talks. For large group and more formal presentations, the 35–45 minute PowerPoint™ presentation developed by the NC Chapter of the ACNM was used. An inexpensive snack was provided at each practice.

In an effort to educate the general public, 22 community "Folic Acid Ambassadors" were trained, given materials to spread the folic acid message throughout their communities. The training kits included a video with script, educational and resource materials. Presentations were made to church circles, school groups, civic clubs, college sororities, family planning classes and child caregivers. Each Ambassador received a stipend.

Finally, a regional mass media campaign that included radio spots, print ads and billboards was developed with the help of the Mission St. Joseph's Marketing Department. The 30 second CDC *Before You Hear It* PSA was used with a 30 second add-on message specifically addressing females in western NC. In order to maximize coverage, the spots ran for three consecutive weeks, off for two weeks and then back on for three weeks. Station audience statistics were studied to determine when to place ads to target 15–44 year old females. The March of Dimes *Daisy Fuentes* ad was used in two weekly entertainment publications.

For more information please contact: Linda Morgan at The Fullerton Genetics Center, linda.morgan@msj.org, 828-213-0031 ♦

Delia's day begins at 5:30 am—waking up ready to attack the day ahead. By 6, she is cathed for the first out of 4 times during the day. Delia lacks control of her bladder due to the level of opening in her spine. She is unable to control the sphincter muscle, which would normally allow her to fully empty her bladder. Taking Ditropan at each catheterization helps control her need to urinate, allowing us to empty her bladder fully every four hours through catheterization. Delia also takes an antibiotic each day to guard against urinary tract and bladder infections—the risk for these infections is heightened because of the invasive cathing process. We strive to provide the most sterile environment possible each time we cath. However, Delia still contracts an infection 4–6 times a year.

After cathing, David helps her dress. Delia is still learning to maneuver her legs when putting on pants and shorts. David puts Delia into her long-leg braces. Usually, by 6:45 am, Delia and I leave for work or school. I work for my family's heating and air conditioning company, so Delia is able to come to work with me on the days she doesn't attend school at the Children's Center.

Once we get to work, Delia hangs out with my dad, Papaw, while they have devotions and pray. Once all the work crews leave for job sites, my mom or I start by setting Delia up in the stander. Basically, she is strapped behind her calves and back/butt into a standing position while in her braces. Time spent in the stander builds tone in Delia's muscles allowing her to place more and more weight on her legs and sustain that weight longer. Delia spends one hour in the stander twice a day.

Next, Delia uses her walker. She maneuvers around things, tests her endurance, practices coming from a sitting to standing position and vice-versa. She practices turning, going up inclines and descending. Delia walks with her walker very well, but often gets distracted and dawdles, so we encourage her to remain focused on the task at hand. After another cathing, Delia uses her therapy bench to practice crawling over obstacles in and out of braces, sitting down and standing up in braces using only support from a person's hand. She kneels at the bench for balance and stretches to reach things in the air which strengthens her abs. As you can see, Delia leads an active, exercise oriented life. Our focus is to strengthen muscles that Delia will not naturally strengthen by developing typically. She has some sensation in one leg, but lacks control and use of both for walking.

Toward the end of Part One of the day, we stretch and massage her feet and heel cords. Around noon, Delia watches a video and eats lunch. She plays for a while before cathing at 2 pm and then we repeat the process. By 4:30–5 pm, it is time for dinner and for Delia and me to leave work. We get home around 6 pm and cath immediately. Then David and I give Delia a bath, get her dressed for bed and help her brush her teeth. Delia watches a video before bed around 7 pm and then it's lights out.

I don't know if what I've described is a *typical* day for Delia—because each day is always different. There are always appointments with doctors, therapy visits, trips with me to run errands for work, March of Dimes meetings and events, school... the list goes on.

Imagine for a moment, a woman discovers she is pregnant with a child with spina bifida. Not only will she be having a baby, but she'll have a child with an *incredible* list of responsibilities attached to its survival. Wouldn't it have been better if she had known that by taking a multi-vitamin everyday the risk of spina bifida could have been lessened by up to 75%? ♦

by Delia Elizabeth Mims

Update... North Carolina NTD Recurrence Prevention Program

As of August 2001, over approximately 155 women have been referred to the North Carolina Neural Tube Defect Recurrence Prevention Program, located within the Genetic Health Care Unit of the North Carolina Division of Public Health.

At this point in time, nearly all of our families who have children with an encephalocele and/or spina bifida have received an extensive array of materials and have had telephone follow-up. Materials sent to these families include educational materials about neural tube defects (books, pamphlets, directories), recommendations for support services, folic acid recommendations, vitamins, and information regarding the option of being seen for a genetic consult if one had not yet been conducted.

On another front, we have continued to recruit data from various tertiary medical centers in North Carolina that diagnose NTDs prenatally. We are in the process of finalizing our protocol for reach-

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www.getfolic.com

At first glance, organizing a website may seem like a fairly routine undertaking—after all, most people seem to have one these days. However, maintaining an attractive, informative, understandable and accessible site is not as easy as it seems. A great deal of hard work has gone into the Council's new website. Amir Pirazeh of Tisfoon Ulterior Systems and Lisa Richardson, Nutrition Section, Women's and Children's Health have spent long hours perfecting our site. Their work is still in progress—new, high-level edits will continue to be done over the next year. With these latest revisions, there's little doubt that the site has the potential to be one of the *best folic acid sites* in the country. Be sure to bookmark our site and refer to it often for campaign updates and great information. ♦

A recent article published in the *Journal of the American Medical Association* (JAMA) concluded that a 19% reduction in NTDs occurred following the folic acid fortification of the United States food supply. The article provided statistics from the 1999 National Health and Nutrition Examination Survey, which

documented a dramatic rise in the serum

SCIENCE Corner



and red blood cell folate levels of reproductive-aged women in the United States following folic acid fortification of enriched grain products. This increase lends support to two previous studies that also noted higher serum folate levels resulting from fortification. It is not presently known whether the observed increases in serum folate levels is enough to maximize NTD prevention. However, red blood cell folate level measurements taken early in a woman's pregnancy have shown a dose-response relationship to the risk of giving birth to an infant with an NTD, with the lowest risk occurring in women with the highest red blood cell folate levels. The authors caution that factors other than fortification may have contributed to the decline in NTD birth prevalence. The article abstract can be viewed at:

<http://jama.ama-assn.org/issues/v285n23/abs/joc10010.html> ♦

We've Come a Long Way Team

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- Media efforts reached well **over two and a half million citizens** in North Carolina with the folic acid message.
- Statewide the folic acid message was on **121 billboards, 106 movie theater screens**, Raleigh-Durham & Charlotte airports and a large number of newspapers statewide.
- Additionally, a mailing including flyers, posters and information was sent to **550 dental hygienists, 120 partnership for children agencies and 65 child care resource and referral centers**. Over **6,000 magnets** were distributed through child-care centers across the state. Plus, a website and new toll-free line were set up, a new logo designed, posters and a media campaign created, AND a statewide Governor's Conference on Folic Acid coordinated. **...WHEW!**

Along with all this activity came many lessons as to what worked, what didn't and what can be done in the future to troubleshoot challenges. Council members now know how to find the best priced vitamins, convince a business to join the campaign, place articles in newspapers, get billboards up and, most importantly, how to work together. The campaign's success is a direct result of the hard work of many dedicated people across the state.

There is little doubt that there are women among the over two million people who saw the folic acid media campaign who decided to change their health behavior and began to take a multivitamin containing folic acid every day. Hundreds of thousands of pieces of our information and campaign items are in the hands of women across the state—a reminder to them to take their vitamin today, tomorrow AND every day. Most certainly, the funds invested in the campaign this spring have already made a difference in the lives the North Carolina mothers who will give birth to healthy babies next year. Congratulations on a great job to date and let's continue toward our goal of having more of North Carolina's babies beginning their lives safe, sound and strong. ♦

Folic Acid Conference participants.



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We'd Love to Hear From You!

Please call us at 1-866-GETFOLIC or contact us online at www.getfolic.com with your comments about the newsletter, suggestions for our next issue and/or to get involved in the North Carolina Folic Acid Campaign.

ON THE ROAD WITH A FOLIC ACID FIELD COORDINATOR...

by Leah Randolph

So you think the position of a Folic Acid Field Coordinator for the March of Dimes is easy, eh? Well, let me give you an up-close and personal look at my recent daily routine. As I'm sure you are all aware, this past spring the folic acid mini-grant season was put on full speed ahead. After intensive coordinator's training, my head was spinning with just what this position had in store! Finally I had the opportunity to raise awareness about neural tube defects and the wonders of folic acid. The next day, I was listing and calling and listing and calling. My throat was sore by the close of the day, but the burn of excitement was fueled inside me.

Then it happened—suddenly, my phone came alive! Although the application was "quick and easy" to complete, the applicants came up with questions I never dreamed of. The application deadlines finally came and went, and all coordinators were called in to assist in the review process.

After a grueling all-day event, decisions were made about funding distribution. I felt as if my heart had spent the entire day in cardiac arrest. Never before had I felt so personally invested in my work. By that point, I considered many of the grantees to be friends, some of which I had had daily contact with for the past few weeks. It was thrilling to finally make the phone calls, telling my contacts about the money they would be receiving.

When the grantees received their funding in April—the pressure was on! Implementation of all grants had to be fully completed by (WHAT?!)...June! Materials had to be distributed, vitamins purchased, presentations and exhibits scheduled, etc., etc. Many of the grantees needed assistance desperately as the evil June deadline lurked in the too near future. Panic set in. I wished for a scientific miracle so that I could be cloned a few hundred times.

My schedule became packed almost daily with presentations (sometimes twice a day), just to insure that the grantees' objectives were being met. People were coming out of the woodwork to receive free vitamins and to gain this new information. I pressed on—presenting, calling, answering calls pertaining to detailed questions, driving to pick up vitamins and insure their prompt delivery to remote places that I never knew existed.

By the end of June my duties as Field Coordinator were done. Although the job was one of the toughest I had ever taken on—I felt a combination of emotions. While I felt a pleasant sense of accomplishment, I continued to worry about the lack of information reaching rural areas. I know my work has made only a small dent in the overwhelming task of decreasing neural tube defects in our state. There is still so much work that needs to be done!

Looking back, the job was more than worth it. By igniting interest out in the communities, I made many wonderful friends and shared so much more than just folic acid education. I just can't describe how rewarding it has been to see the faces of the folks who truly want to learn. Their smiles have truly made an impression in my heart, and fueled my desire to educate women about folic acid. ♦

Ed: Special thanks to Dennis Stevenson, Lisa Adams and Rhonda Beamon—our three other great field coordinators. Thanks for a job well done to the four of you!

1-866-GET-FOLIC



FOLIC ACID. IT'S NOT JUST FOR BABIES ANYMORE.

Taking a multivitamin with 400 mcg of folic acid every day before pregnancy can do more than help prevent serious birth defects. It can also help protect you against heart disease, stroke, even certain kinds of cancer. So even if you're not planning to become pregnant, get your daily dose of folic acid. To learn more, ask your health care provider or local health department, call 1-866-GET-FOLIC or go to www.getfolic.com.

FOLIC ACID  **GET IT NOW**



A sample of Crittenden Advertising's excellent work!

KNOWLEDGE & USE of FOLIC ACID AMONG NORTH CAROLINA'S WOMEN

The 1999 North Carolina PRAMS survey, an ongoing survey of North Carolina resident women who have delivered a live born infant within the previous three months, provides a wealth of important information for the NC Folic Acid Campaign. The survey presents data on mothers' knowledge of folic acid, sources of information on folic acid and preconceptional intake of multivitamins or folic acid supplements. It indicates that approximately 77% of all women had heard or read about the benefits of folic acid. Just slightly over one-half of all women reported that they had heard about folic acid from their doctor or health care provider. However, only about 26% of women took folic acid every day prior to pregnancy. Also noted were marked differences among various sociodemographic groups with respect to knowledge and intake of folic acid. Mothers who were older, better educated, married and had higher incomes were most likely to have heard about folic acid and to have taken it every day before pregnancy. ♦

Crittenden Advertising, Inc. is a true hero for North Carolina's babies. This amazing company has donated tens of thousands of dollars worth of time and talent to the folic acid campaign this spring. David Crittenden and his team designed the new look, logo, billboards, posters, PSA slicks, stickers and reminder items for the campaign as well as a marketing plan. They secured the "Get Folic" website and toll-free line numbers and worked with the March of Dimes to find excellent prices for printing and supplies. They have helped the Executive Committee negotiate "new" worlds of media and have worked individually with many Council members in communities across the state. Their commitment to mothers and babies is strong as they continue to be active partners in the campaign. Thanks to David, Maggie, Tom, Robin and the whole Crittenden team!

Winn-Dixie is the foundation partner for the Greater Piedmont Folic Acid Campaign. Winn-Dixie was responsible for getting hundreds of free bottles of vitamins directly into women's hands and for educating thousands more about the importance of folic acid. As part of their contribution to the campaign, Winn-Dixie designed and printed 180,000 "free vitamin" coupons. With them, over a 6-week period, any woman could redeem the coupon at a Winn-Dixie pharmacy and receive a free bottle of vitamins. Additionally, they helped secure a significant discount for a bulk purchase of vitamins and displayed folic acid posters and other materials in their pharmacies. Hats off to Joe Richards, Brent Clevenger, Winn-Dixie cashiers, pharmacists and store managers!

Tri-State Outdoor Advertising, Inc., Fairway Billboards and the National Cinema Network gave the Council very generous media contracts.

Agencies entered into partnerships with a wide variety of organizations to promote the folic acid message. Thanks go to the following businesses for their partnership: **Food Lion, Kmart, Wal-Mart, Kindercare, Alltel, Abbott Industries, Slender World, Gold's Gyms, CVS, Kerr Drugs, Tyson Foods, Eckerd's, Lowes Foods, and Hardees.** For more information about the kind of contribution made by these great businesses, please call our toll-free line!

This past spring the following have played an important role in the success of the campaign: Western NC Wellness Council, local Healthy Carolinian committees, local Partnership for Children agencies, libraries, specialty stores run by Hispanic owners, pharmacies, local departments of social services, register of deeds offices, town festivals and community

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A Pat on the Back...our SPECIAL PARTNERS

WHAT DID YOU THINK ????

About the many different "reminder" items available this spring? Cast your vote on which items you liked the best—notepads, stickers, water bottles, magnets, toothpaste squeezers, key chains, computer screen sweeps and pens on a rope?

Let us know at 1-866-GET FOLIC ♦

Advocacy Corner *continued from p. 1*

share information about these programs and concerns with legislators while they are in Raleigh as well as in their home districts.

Special thanks to the *News & Observer*, WRAL and the *Chapel Hill News* for ongoing coverage of our issues. The general public has taken a marked interest in these programs as a result of the excellent media coverage. Also, a BIG THANK YOU to Jolyne and Elizabeth Wagner and Susan and Christa Gibbs for their incredible willingness to speak on camera at a moment's notice about this important issue. ♦

1-866-GET-FOLIC

**FOLIC
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www.GetFolic.com**Special Partners** *continued from p. 5*

health fairs, Work First programs, a farmer's market, health education teachers, local hospitals, wellness centers, a variety of local clinics, Infant Mortality Reduction Coalitions, Baby Love Plus Program, Head Start, a housing authority, a juvenile detention center, two dance troupes, Cooperative Extensions, Mother WIT Community Development program, the Hunger Coalition and the Living Water Family Resource Center and more—**THANK YOU ALL!** ♦

Update... NTD Recurrence Prevention *continued from p. 3*

ing these women and will begin this phase of the program in the near future.

Finally, we have formed alliances with two strong partners in the care of these women and families. First, we have formed a good relationship with Dr. Nancy Chescheir of the UNC School of Medicine. Dr. Chescheir has been and continues to be interested in surgeries involving the in-utero repair of neural tube defects. UNC was recently approved by their hospital IRB to perform 10 cases of in-utero NTD surgical repair. So far eight of the ten surgeries have been performed. Dr. Chescheir is trying to push for a national clinical trial of the NTD in-utero surgery, and is trying to ensure that UNC be a part of such a trial. The goal of such a trial is to scientifically determine the surgery's risks and benefits; to date the surgery is considered experimental only. The NTD Recurrence Prevention Program is proud to be working with Dr. Chescheir. Secondly, the Recurrence Prevention Program has recently partnered with the North Carolina Child Service Coordination Program, which is a long-standing program within the Children and Youth Branch of the Division of Public Health aimed at linking North Carolina services and support to those children who qualify. The CSC program works with children from birth to age five, and aids in finding medical care, transportation, childcare and/or financial aid.

We are excited about the progress made by the NTD Recurrence Prevention Program, yet we know there is much work to be done to both lower the incidence of NTDs in North Carolina as well as more effectively support these women/families who have had a pregnancy or a child with a neural tube defect. Questions or comments about the program are always welcome: you may contact the program coordinator, Karen Powers, MS, via phone at 919-715-3903 or email at: karen.powers@ncmail.net.



Publisher The North Carolina Folic Acid Council
Editor Sarah Verbiest
Project Coordinator Cindy Chambers
Design/Layout R. Leishman Design

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